ETHICAL RESEARCH INVOLVING CHILDREN

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Interviewing children with disability in the presence of a parent

Background context:

Traditionally, social researchers expected parents or other adults to act as proxies for the authentic voices of children with disability. Such exclusionary approaches to childhood disability research were often grounded in assumptions about the inability of children with disability to have or express their opinions. In recent decades a growing body of participatory research has used a range of creative methods for engaging with children with disability and upholding their right to have their voices heard. When planning to conduct interviews with children with disability, the dynamics of whether or not to have a parent present are an important consideration. In some cases parents assume they should be present because they are expected to provide information on behalf of their child. Parents may also be interested in hearing their child's views or be concerned about their child's safety or support needs. Alternatively, a child may choose to have their parent present as they are a trusted adult who knows them well and who can provide support. The researcher may also wish to have a parent present to provide reassurance for the child or to help understand their child's preferred communication method. However, children with disability should still have the same opportunities as children without disability to express a preference about whether they would like their parent present during a research interview. The views of children with disability are likely to be different to those of their parents and they may prefer to share their views with the researcher without the surveillance of their parent. This case study is drawn from a research study that examined the provision of family support services for children with intellectual disability in Northern Ireland. A key objective of the research was to ascertain the views of children and consult them about their experiences of family support services.

The ethical challenge:

The study involved interviews with children with intellectual disability over the course of three visits in the family home. Before visiting children, the researcher discussed the research process with parents and explained that some children may wish their parent to be present and others may not. The researcher explained that the child would make a decision on this matter, but would also be free to change their mind. On first visits, the researcher consulted each child about their preference of being interviewed on their own or having their parent present. In one case a child indicated a preference to meet the researcher on their own.

The researcher informed the parent of their child's preference and agreed with the parent that they would meet their child alone on the next visit. On the second visit, after welcoming the researcher into the family home, the parent continued to stay in the same room with the child and researcher. The researcher was unsure if the parent had forgotten their earlier discussion about meeting their child on their own or if they still assumed they should remain present. The researcher had to decide how best to address this issue without causing distress for either the child or parent. She was also mindful that her response to this ethical dilemma would send a message to the child about whether the researcher respected and prioritised their views and preferences which could impact on the child's participation in the interview.

The researcher could proceed with the interview and ignore the issue of parental presence unless the child raised it as a problem. This approach would avoid confrontation and ensure the parent did not feel excluded. However, this approach would fail to prioritise the child's preference and could impact on their interview responses as the adults present would be in control of the research process. Instead, the researcher could speak with the parent on their own to explain the research process again and offer them an opportunity to discuss any concerns. However, this may lead the child to believe that the adults are privately discussing their involvement in the research and reaching a decision without including them. An alternative choice would be to address the issue with the child and parent both present. This option may lead the child to feel they have upset their parent by excluding them and to feel pressured to change their mind. However, this approach would ensure that the issue is addressed in a transparent way with both the child and parent.

Choices made:

The researcher chose the latter option, with both the child and parent present. She took great care to approach the subject in a sensitive and supportive manner. Explaining that the child's views were the main priority for the researcher and reminding the child and parent about the child's expressed preference on the previous visit was a good starting point. The parent explained that they had become accustomed to remaining present during visits from professionals as it was usually assumed that they would provide information on behalf of their child, especially when there were concerns that their child may not be able to answer some questions. The researcher explained the purpose of the research again and emphasised that she was primarily interested in their child's views and it was fine if their child was not able to answer all of the questions or did not wish to answer some questions. The child also advised their parent that they felt comfortable being on their own with the researcher as a range of communication tools were provided to support their participation, including drawing, sentence completion, computer-assisted techniques and sign cards. Following this discussion, the parent was happy to leave the room and for their child to meet the researcher on their own for the next two visits.

Reflexive questions/considerations:

- Power dynamics between children with disability and parents are an important consideration during interviews in the family home. Parents can be an important source of support for children with disability and help to facilitate their participation in research interviews. However, they may also dominate the discussion by re-interpreting or correcting their child's responses.

- Researchers need to use creative methods to engage children with disability in the research process and ensure that their views are prioritised whether or not their parent is present.

- Decisions researchers make when presented with conflicting child and adult opinions send a powerful message to children with disability about their involvement in, and control of, their participation in the research process.

- The expressed preferences of children with disability about how to participate in the research process should be respected.

- What could the researcher have done if the child or parent became upset during the discussion about the child being interviewed alone?

- If the parent insisted on being present, what could the researcher do? Would it be appropriate to conduct the child's interview with the parent present knowing it was not the child's preferred approach?

- In cases where children prefer their parent to be present, what techniques could the researcher use to ensure the views of the child are prioritised?

- What are the risks for the researcher when meeting children on their own?

References

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